

General

Title

Children with special health care needs: percentage of children who meet criteria for having special health care needs according to the Children with Special Health Care Needs Screener (CSHCN Screener).

Source(s)

Child and Adolescent Health Measurement Initiative (CAHMI). Approaches to identifying children and adults with special health care needs. A resource manual for state Medicaid agencies and managed care organizations. Baltimore (MD): Child and Adolescent Health Measurement Initiative (CAHMI); 2002. various p.

Measure Domain

Primary Measure Domain

Population Health

The validity of measures depends on how they are built. By examining the key building blocks of a measure, you can assess its validity for your purpose. For more information, visit the Measure Validity page.

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to efficiently identify children with ongoing physical, mental, behavioral or other conditions who also require a type or amount of health and related services beyond that required by children generally.

The CSHCN Screener is a five item, parent-reported tool which identifies children who currently experience one or more of five common health consequences: (1) use or need of prescription medication; (2) above average use or need of medical, mental health or educational services; (3) functional limitations compared with others of same age; (4) use or need of specialized therapies (occupational therapist [OT], physical therapist [PT], speech, etc.); (5) needs treatment or counseling for emotional, behavioral, or

developmental problems. Any of the 5 health consequences must be due to a physical, mental, behavioral or other type of health condition which has lasted or is expected to last at least 12 months. The questions are designed to be self-administered or telephone administered as part of a parent/caretaker survey. The screener takes approximately one minute to administer for a single child and an average of two minutes to complete when screening all children in a household.

English and Spanish language versions of the screening tool are available.

Rationale

Children with special health care needs (CSHCN) are an important population of interest for health care services, economic health analyses, and policy development and implementation. CSHCN often have limited access to health care or do not receive all needed health services because of their elevated need for health care due to having a wide range of chronic illnesses, disabilities and other health problems. Thus, early identification, follow-up, and potential case management are essential to improve their quality of life. Also, continuity and coordination of care and utilization of appropriate payment mechanisms cannot be ensured unless these individuals are accurately identified. Providing appropriate services based on early identification may reduce the cost of treating children with special needs. A single, approved standardized screening instrument to identify CSHCN required for Federal and State program planning and evaluation was developed to monitor CSHCN health status and provide quality of care as mandated in the Title V of the Social Security Act.

The CSHCN Screener was developed to reflect the federal Maternal and Child Health Bureau's (MCHB) consequences-based definition of children with special health care needs: "Children who have special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

The CSHCN Screener tool focuses on the current consequences of chronic health conditions. The non-condition specific approach used by the CSHCN Screener identifies children across the range and diversity of childhood chronic conditions and special needs, allowing a more comprehensive assessment of health care system performance than is attainable by focusing on a single diagnosis or type of special need. In addition, the relatively low prevalence of most childhood chronic conditions and special health care needs often makes it problematic to find adequate numbers of children with a specific diagnosis or type of special need. A non-condition specific approach makes it possible in many cases to identify enough children to allow statistically robust quality comparisons across health care systems and/or providers.

Primary Clinical Component

Children with chronic or special health care needs; consequence-based criteria screening

Denominator Description

Children less than or equal to 17 years of age whose parent/caretaker completed the Children with Special Health Care Needs Screener (CSHCN Screener)

Numerator Description

Children who currently experience one or more of the following common health consequences:

Use or need of prescription medication

Above average use or need of medical, mental health or educational services

Functional limitations compared with others of same age

Use or need of specialized therapies (occupational therapy [OT], physical therapy [PT], speech, etc.)

Needs treatment or counseling for emotional, behavioral, or developmental problems

AND

The above mentioned consequence results from a chronic physical, developmental, behavioral, emotional or any kind of health condition lasting or expected to last for at least 12 months.

Evidence Supporting the Measure

Evidence Supporting the Value of Monitoring the Aspect of Population Health

A formal consensus procedure involving experts in relevant clinical, methodological, and organizational sciences

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Evidence Supporting Need for the Measure

Need for the Measure

Monitoring health state(s)

Variation in health state(s)

Evidence Supporting Need for the Measure

Bethell CD, Read D, Neff J, Blumberg SJ, Stein RE, Sharp V, Newacheck PW. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions--revised. Ambul Pediatr. 2002 Jan-Feb;2(1):49-57. PubMed

Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. Ambul Pediatr. 2002 Jan-Feb;2(1):38-48. PubMed

Blumberg SJ, Bramlett MD. Comparing states on outcomes for children with special health care needs. Matern Child Health J. 2005 Jun;9(2 Suppl):S121-8. PubMed

McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. A new definition of children with special health care needs. Pediatrics. 1998 Jul;102(1 Pt 1):137-40. PubMed

van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. Arch Pediatr Adolesc Med. 2004 Sep;158(9):884-90. PubMed

van Dyck PC, McPherson M, Strickland BB, Nesseler K, Blumberg SJ, Cynamon ML, Newacheck PW. The national survey of children with special health care needs. Ambul Pediatr. 2002 Jan-Feb;2(1):29-37. PubMed

State of Use of the Measure

State of Use

Current routine use

Current Use

Decision-making by managers about resource allocation

External oversight/Indian Health Service

External oversight/Maternal and Child Health Bureau

External oversight/Medicaid

External oversight/Regional, county, or city agencies

External oversight/State government program

Federal health policymaking

Monitoring and planning

Monitoring health state(s)

National reporting

State health policymaking

Application of Measure in its Current Use

Care Setting

Ambulatory Care

Ancillary Services

Behavioral Health Care

Community Health Care

Emergency Medical Services

Home Care

Hospitals

Managed Care Plans

Physician Group Practices/Clinics

Rehabilitation Centers

Residential Care Facilities

Rural Health Care

Substance Use Treatment Programs/Centers

Professionals Responsible for Health Care

Measure is not provider specific

Lowest Level of Health Care Delivery Addressed

Individual Clinicians

Target Population Age

Ages less than or equal to 17

Target Population Gender

Either male or female

Stratification by Vulnerable Populations

Unspecified

Characteristics of the Primary Clinical Component

Incidence/Prevalence

Nationally, 12.8% to 19.2% of children ages 0 to 17 years meet criteria having special health care needs according to National Surveys (National Survey of Children's Health [NSCH], National Survey of Children with Special Health Care Needs [NS-CSHCN], Medical Panel Expenditure Survey [MEPS]) conducted between 2001 and 2007.

See also the "Association with Vulnerable Populations" and "Burden of Illness" fields.

Evidence for Incidence/Prevalence

Bethell CD, Read D, Blumberg SJ, Newacheck PW. What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. Matern Child Health J. 2008 Jan;12(1):1-14. PubMed

National Survey of Children's Health: Interactive data search of the 2007 data. Available at: http://www.nschdata.org/DataQuery/SurveyAreas.aspx?yid=2. [internet]. Child and Adolescent Health Measurement Initiative; [accessed 2011 Mar 03].

van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. Arch Pediatr Adolesc Med. 2004 Sep;158(9):884-90. PubMed

Association with Vulnerable Populations

According to the 2007 National Survey of Children's Health (NSCH):

Children with special health care needs (CSHCN) are less likely to receive care within a medical home

— only 49.8% of CSHCN receive such coordinated and ongoing care, compared with 59.4% of children living without special needs.

Boys are more likely to have special health care needs than girls - 22.2% versus 16.0%, respectively.

CSHCN are more likely than non-CSHCN to have public health insurance -35.7% of CSHCN have public insurance, compared to 27.5% of non-CSHCN.

More children who live in families with income of below poverty level have special health care needs. 20.8% of children living in families with 0 to 99% federal poverty level (FPL) have special health care needs, compared with 18.6% to 18.9% of children living in families with above 100% FPL.

Children who live in families with two biological or adoptive parents are less likely to have special health care needs (16.3%), compared to the children who live in families of two parents with at least one step-parent (23.2%) and single mother (25.9%).

See also the "Burden of Illness" field.

Evidence for Association with Vulnerable Populations

National Survey of Children's Health: Interactive data search of the 2007 data. Available at: http://www.nschdata.org/DataQuery/SurveyAreas.aspx?yid=2. [internet]. Child and Adolescent Health Measurement Initiative; [accessed 2011 Mar 03].

Burden of Illness

According to the 2007 National Survey of Children's Health (NSCH):

Children with special health care needs (CSHCN) aged 6 to 17 are twice as likely to repeat a grade in school than non-CSHCN (18.5% versus 8.2%, respectively).

CSHCN aged 6 to 17 are nearly 4 times as likely to miss 11 or more school days a year due to illness or injury compared to non-CSHCN (13.5% versus 3.5%, respectively).

2005/06 National Survey of Children with Special Health Care Needs (NS-CSHCN) indicates that:

18.1% of CSHCN live in families where their conditions have caused financial problems for the family. 23.8% of CSHCN live in families where one or more members had to cut back or stop working due to children's condition.

These adverse child and family-level impacts were concentrated among low-income and uninsured CSHCN.

Complexity of CSHCN:

84.7% of CSHCN have one or more functional difficulties. More specifically, of CSHCN with functional difficulties 67.8% have bodily difficulties, 58.2% activity and participation difficulties and 49.3% other emotional and behavioral difficulties.

60.3% of CSHCN have more complex needs that require multidisciplinary care team, and/or specialized services beyond prescription medications.

63.1% of CSHCN experience multiple (two or more) current chronic health conditions from the specified 21 conditions, and 77.1% of those children's parents reported that their conditions are moderate or severe.

Evidence for Burden of Illness

Bramlett MD, Read D, Bethell C, Blumberg SJ. Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. Matern Child Health J. 2009 Mar;13(2):151-63. PubMed

National Survey of Children with Special Health Care Needs: Interactive data search of the 2005/06 data. Available at: http://www.cshcndata.org/DataQuery/SurveyAreas.aspx?yid=2. [internet]. Child and Adolescent Health Measurement Initiative; [accessed 2011 Mar 03].

National Survey of Children's Health: Interactive data search of the 2007 data. Available at: http://www.nschdata.org/DataQuery/SurveyAreas.aspx?yid=2. [internet]. Child and Adolescent Health Measurement Initiative; [accessed 2011 Mar 03].

van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. Arch Pediatr Adolesc Med. 2004 Sep;158(9):884-90. PubMed

Utilization

Use of health care for children with special health care needs (CSHCN) compared to non-CSHCN:

Four times the number of hospitalizations (89 versus 22 discharges per 1000)

Spent more than 7 times as many days in hospitals (370 versus 49 days per 1000) and more than half (52.5%) of children's hospital days were accounted for CSHCN

More than twice as many physician visits annually (4.35 versus 1.75)

Seven times more non-physician visits (2.17 versus 0.30) annually

More than 5 times the number of prescribed medications per year (6.94 versus 1.22)

Used substantially more home health provider days (1.73 versus 0.002); approximately 87% of home health care days were accounted for by CSHCN

Evidence for Utilization

Bramlett MD, Read D, Bethell C, Blumberg SJ. Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. Matern Child Health J. 2009 Mar;13(2):151-63. PubMed

Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. Arch Pediatr Adolesc Med. 2005 Jan;159(1):10-7. PubMed

Costs

Medical expenditure for children with special health care needs (CSHCN) compared to non-CSHCN (MEPS):

Total health care expenditures 3 times more (\$2099 versus \$628)

Hospital care expenses 4 times higher (\$361 versus \$96)

Physician services expenses more than double the amount (\$406 versus \$150)

Six times greater non-physician services expenses (\$144 versus \$24)

Average expenditures on prescribed medications 10 times higher (\$340 versus \$34)

Average expenditures for other medical services were about twice (\$37 versus \$16)

Families of CSHCN are 2 to 3 times more likely to have high out-of-pocket expenses (greater than \$1000 per year, greater than 5% of family income). Children in households with incomes less than 200% of the federal poverty level (FPL) spent about 164% more of their family's income on health care, and those living in households with incomes between 200% and 400% of the FPL spent about 46% more than their counterparts in households with incomes at or above 400% of the FPL.

Medical expenditures for CSHCN who qualify on 4 of the 5 screener domains are almost four times those of CSHCN who qualify on only one screening criterion (\$7881 versus \$1952, respectively).

Evidence for Costs

Bramlett MD, Read D, Bethell C, Blumberg SJ. Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. Matern Child Health J. 2009 Mar;13(2):151-63. PubMed

Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. Arch Pediatr Adolesc Med. 2005 Jan;159(1):10-7. PubMed

Institute of Medicine (IOM) Healthcare Quality Report Categories

IOM Care Need

Living with Illness

Staying Healthy

IOM Domain

Effectiveness

Patient-centeredness

Data Collection for the Measure

Case Finding

Both users and nonusers of care

Description of Case Finding

Children less than or equal to 17 years of age whose parent/caretaker completed the Children with Special Health Care Needs Screener (CSHCN Screener)

Denominator Sampling Frame

Geographically defined

Denominator Inclusions/Exclusions

Inclusions

Children less than or equal to 17 years of age whose parent/caretaker completed the Children with Special Health Care Needs Screener (CSHCN Screener)

Exclusions

Adults 18 years of age and older

Relationship of Denominator to Numerator

All cases in the denominator are equally eligible to appear in the numerator

Denominator (Index) Event

Encounter

Denominator Time Window

Time window is a single point in time

Numerator Inclusions/Exclusions

Inclusions

Children who currently experience one or more of the following common health consequences:

Use or need of prescription medication

Above average use or need of medical, mental health or educational services

Functional limitations compared with others of same age

Use or need of specialized therapies (occupational therapy [OT], physical therapy [PT], speech, etc.) Needs treatment or counseling for emotional, behavioral, or developmental problems

AND

The above mentioned consequence results from a chronic physical, developmental, behavioral, emotional or any kind of health condition lasting or expected to last for at least 12 months.

Exclusions

Children age 0 to 17 years who do not meet any of the five criteria for having a special health care need

Measure Results Under Control of Health Care Professionals, Organizations and/or Policymakers

The measure results are not under the control of the health care professionals, organizations and/or policymakers to whom the measure applies.

Numerator Time Window

Encounter or point in time

Data Source

Patient survey

Level of Determination of Quality

Does not apply to this measure

Type of Health State

Pre-existing Instrument Used

Unspecified

Computation of the Measure

Scoring

Weighted Score/Composite/Scale

Interpretation of Score

A lower score is desirable

Allowance for Patient Factors

Analysis by high-risk subgroup (stratification on vulnerable populations)

Analysis by subgroup (stratification on patient factors, geographic factors, etc.)

Description of Allowance for Patient Factors

No stratification is required.

The Children with Special Health Care Needs Screener (CSHCN Screener) administered in its most recent form (in the 2005/06 National Survey of Children with Special Health Care Needs [NS-CSHCN] and 2007 National Survey of Children's Health [NSCH]) includes a number of child demographic variables that allow for stratification of the findings by possible vulnerability:

Age

Gender

Geographic location: State, HRSA Region, National-level Rural Urban Commuter Areas (RUCA)

Race/ethnicity

Health insurance: status, type, consistency, adequacy

Primary household language

Household income

Family structure: Two biological or adoptive parents, two parents with at least one step-parent,

mother only and other

Special Health Care Needs type

Standard of Comparison

External comparison at a point in time

External comparison of time trends

Internal time comparison

Evaluation of Measure Properties

Extent of Measure Testing

Over 36,000 cases of CSHCN Screener data were collected during development of the CSHCN Screener. Testing included administration in commercial and Medicaid managed care, Medicaid Fee-for-Service, and primary care case management populations. The Screener was also fielded in two national samples of households with children during pre-testing for the National Survey of CSHCN sponsored by the federal Maternal and Child Health Bureau.

Results from the CSHCN Screener have been compared with the Questionnaire to Identify Children with Chronic Conditions (QuICCC-R) and the 3M Clinical Risk Groups (3M/CRG) clinical classification system, medical chart reviews and parental reports of their children's specific health conditions, service needs and utilization levels. Overall, the CSHCN Screener identified numbers of children commensurate with other epidemiological studies of special health care needs. The screener did not systematically exclude categories of children according to the type and/or severity of their health conditions, and exhibited a high level of agreement with other methods. Good internal psychometric properties of responses to the CSHCN Screener and minimal random measurement error of the Screener was identified on the study using data from 2005-2006 NS-CSHCN (e.g., Cronbach's coefficient a level greater than .80).

Since initial development of the Screener, over 1 million cases of screener data have been collected through the NS-CSHCN (735,357), NSCH (193, 995) and MEPS (84,020) and have been used to continuously reassess its performance and validity.

Evidence for Reliability/Validity Testing

Bethell CD, Read D, Neff J, Blumberg SJ, Stein RE, Sharp V, Newacheck PW. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions--revised. Ambul Pediatr. 2002 Jan-Feb;2(1):49-57. PubMed

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Blumberg SJ, Olson L, Frankel M, Osborn L, Becker CJ, Srinath KP, Giambo P. Design and operation of the National Survey of Children with Special Health Care Needs, 2001. Vital Health Stat 1. 2003 Jun; (41):1-136. PubMed

Carle AC, Blumberg SJ, Poblenz C. Internal psychometric properties of the children with special health care needs screener. Ambul Pediatr. 2010 Mar 13;:Epub ahead of print. PubMed

Child and Adolescent Health Measurement Initiative (CAHMI). Approaches to identifying children and adults with special health care needs. A resource manual for state Medicaid agencies and managed care organizations. Baltimore (MD): Child and Adolescent Health Measurement Initiative (CAHMI); 2002. various p.

Read D, Bethell C, Blumberg SJ, Abreu M, Molina C. An evaluation of the linguistic and cultural validity of the Spanish language version of the children with special health care needs screener. Matern Child Health J. 2007 Nov;11(6):568-85. PubMed

Identifying Information

Original Title

Children with special health care needs screener (CSHCN Screener).

Submitter

Child and Adolescent Health Measurement Initiative - Nonprofit Organization

Developer

Child and Adolescent Health Measurement Initiative - Nonprofit Organization

Funding Source(s)

The CSHCN Screener was initially supported by The David and Lucile Packard Foundation and validation and re-assessment of the Screener were funded by the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), the National Center for Health Statistics (NCHS) and the Centers for Medicare & Medicaid Services (CMS) of the Department of Health and Human Services.

Composition of the Group that Developed the Measure

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Financial Disclosures/Other Potential Conflicts of Interest

None

Adaptation

Measure was not adapted from another source.

Release Date

2000 Oct

Measure Status

This is the current release of the measure.

Source(s)

Child and Adolescent Health Measurement Initiative (CAHMI). Approaches to identifying children and adults with special health care needs. A resource manual for state Medicaid agencies and managed care organizations. Baltimore (MD): Child and Adolescent Health Measurement Initiative (CAHMI); 2002. various p.

Measure Availability

The individual measure, "Children with Special Health Care Needs Screener (CSHCN Screener), is
published in "Approaches to Identifying Children and Adults with Special Health Care Needs. A Resource
Manual for State Medicaid Agencies and Managed Care Organizations." This document is available in
Portable Document Format (PDF) from the Child and Adolescent Health Measurement Initiative (CAHMI)
Web site

For further information, please contact the Child ar	nd Adolescent Health Measurement Initiative (CAHMI
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NQMC Status

This NQMC summary was completed by ECRI Institute on February 23, 2011. The information was verified by the measure developer on April 12, 2011.

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